

Young people's experiences of managing asthma and diabetes at school

J Newbould, S-A Francis, F Smith

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See end of article for authors' affiliations

Correspondence to:
Dr Jennifer Newbould,
Department of Practice and
Policy, School of Pharmacy,
University of London,
29–39 Brunswick Square,
London WC1N 1AX, UK;
jennifer.newbould@
pharmacy.ac.uk

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Purpose: To examine the experiences and concerns of young people and their parents regarding the management of medication for asthma or diabetes whilst at school.

Methods: Face-to-face semi-structured interviews were conducted with 69 young people aged 8–15 years (43 with asthma and 26 with diabetes) and their parents (138 interviews in total) in their own homes. Respondents were recruited through randomly selected general practice surgeries in contrasting areas in South East England. Interviews were audio-recorded, transcribed verbatim and analysed using established qualitative analytical procedures.

Results: Young people with asthma and diabetes discussed difficulties regarding access to and use of their medicines at school which may jeopardise optimal condition management. School medicines policies could be a further hindrance. Young people endeavour to find ways to accommodate their medication and condition related needs whilst at school, in an attempt to limit the impact of their condition upon school activities such as sport, school trips and relationships with peers. Parents expressed concern regarding the awareness and levels of support available to their sons/daughters, in particular if a crisis should develop.

Discussion: In order to ensure optimal care, there is a need for the development of protocols tailored to the needs of young people with different conditions. These should preferably be devised in partnership between the young person, their parents and the school to ensure that the flexibility and support required for optimal management are offered.

In the home, young people with chronic conditions will manage their medication with assistance from their parents. A number of researchers have identified varying levels of assistance and differing patterns of partnership in these activities.^{1–3} However, whilst at school, in the absence of their parents, young people with a chronic condition may have to assess their need for, manage and administer medication without assistance or support.

British government policy relating to support for young people in managing medication for chronic conditions in schools has been limited. The National Service Framework for Children, Young People and Maternity Services⁴ emphasised the need for schools to carefully consider arrangements for the management of pupil's medication, but there was little elaboration on this point. The most extensive guidance relating to the management of medication in schools has been the publication of *Supporting pupils with medical needs: a good practice guide*.⁵ This document stated that it was the responsibility of the parent to provide the school with information regarding their son's/daughter's health and medical needs and that within the school head teachers were responsible for the medical needs of children. However, the extent and nature of this responsibility was not discussed. The implementation of school policies regarding medication was strongly recommended in the document and guidelines to assist schools in the formulation of policy were laid out.

Researchers have investigated the extent of school policies relating to medication. In a survey of London primary school head teachers,⁶ 95% reported having a policy relating to the medical needs of young people and 50% had individual care plans in place for specific conditions, as advocated by the Department of Education and Employment.⁵ In County Durham, a survey involving 296 head teachers⁷ revealed that all secondary schools and two fifths of primary schools had a policy relating to asthma. A survey of head teachers in Wales⁸

(n = 216) noted that 40% of schools allowed young people to take responsibility for their own inhalers.

Research among young people (n = 33) with a variety of conditions reported that young people generally found ways to manage the effects of their conditions whilst at school. However, they reported difficulties in participating in school activities and in responding to teachers' and peers' attitudes.⁹

For young people in the US with diabetes, attitudes of teachers and their lack of understanding of actions and procedures required for good diabetic control has also been reported to lead to problems in maintaining effective management.¹⁰ These young people also valued the assistance of the school nurse, a person not available in most schools in the UK. The pressures of having a condition such as diabetes have been shown to affect young people's academic performance at school.¹¹

The transition from elementary to middle school has also been reported to lead to increased obstacles to young people's management of asthma. Young people, again in the US, reported the more diffused support, greater peer pressure and increased demands in physical education as greater challenges to the management of their condition in a secondary school setting.¹²

Parents of young people with chronic conditions have also expressed concerns regarding the management of conditions at school. In particular, they attributed many of these concerns to teachers' lack of knowledge about the condition.¹³

In Australia and Canada, schools have been the location for peer led asthma education programmes, which have reported improvements in quality of life for young people with asthma.^{14–15} In the USA, a pilot study in which diabetes care visits were conducted at school, has been shown to improve diabetes management at school and at home.¹⁶ The American Diabetes Association has advocated the use of "individualized diabetes medical management plans", devised and agreed between health professionals and parents to set out guidance for the medical care needs of the young person when at school.¹⁷

Recent UK debate about the management of chronic conditions in schools suggests that despite guidance documents from the government and the creation of school policies, difficulties surrounding medication and condition management in schools are still prevalent.^{18, 19} The need to train school staff regarding the management of chronic conditions and the use of medication has been identified by head teachers and researchers.⁸

The aim of this paper (which was part of a wider study into partnerships between young people and their parents in the management of medication for asthma and diabetes) is to examine the experiences and concerns of young people and their parents in the daily management of medication for asthma or diabetes whilst at school. Specific objectives were to document the views and experiences of young people regarding the management of their medication whilst at school, to identify the concerns of parents regarding the role of the school in supporting their son/daughter in effective management of their condition, and to examine the implications of these experiences for successful management of the condition in the context of school life.

METHODS

Data were collected in face-to-face semi-structured interviews conducted in the participants' own homes. Ethical approval was obtained from the relevant ethics committees (Enfield and Haringey and East and North Hertfordshire) prior to commencement of the study.

Sampling and recruitment

The sampling and recruitment strategy was designed to obtain a representative primary care sample of young people with asthma or diabetes. Young people and their parents were identified through randomly selected general practice surgeries from four health authority areas in South East England²⁰ that were characterised by widely ranging under privileged area (UPA) scores.¹ Participating surgeries were requested to identify from their records young people with either asthma (aged 8–12 years) or diabetes (aged 8–15 years) and send information about the project to the young person and their parents. The age range for the diabetes sample was extended following pilot work due to the lower prevalence rate of the condition. If they were willing to participate, the young person and their parent were asked to return a reply slip, following which the interviewer (JN) contacted them to arrange the interviews.

Study instruments and procedures

Separate interviews with each young person and parent were conducted whenever possible to gain independent perspectives. Consideration was also given to ensuring a methodological approach that would encourage children to communicate with the researcher and express their views. Thus, attention was paid to issues such as the use of language, length of interviews and environment in which data were generated. The interview schedule was devised following a literature review and preliminary fieldwork with parents of young people who were members of voluntary groups and a small number of health professionals involved in the care of these groups. The format was similar for both conditions. Data were gathered on young people's and parents' experiences and views regarding the management of asthma or diabetes at school. Structured questions were asked to obtain information on personal characteristics, storage of medication or items related to the

¹UPA scores record the level of deprivation of an area based on eight factors including the number of unemployed and from an ethnic minority background; a higher UPA score indicates a greater level of deprivation. The UPA scores of the four areas in the study ranged from –19.91 to 17.42.²¹

condition and policies regarding medication in school. Interviews were audio-recorded and transcribed verbatim.

Analysis

Principles of qualitative inquiry were followed in the collection of data with the use of open questions and requests for further details of the views and experiences raised by respondents. The aim of this approach was to obtain an accurate reflection of the views and experiences from the perspectives of respondents.

Qualitative analytical procedures were used in the analysis of open questions. In the first instance, all data relating to the use of medicines and the management of the condition at school were identified in the transcripts. A coding frame was then devised based on the issues, topics and descriptions raised by the respondents. Following primary coding and the identification of principal themes, more detailed examination of the data enabled the researcher to build a secondary coding structure relating to each theme. Data from the young person's and parents' interviews were analysed separately to enable identification of the perspectives and experiences of each. To ensure reliability, a subset of data was coded by all members of the research team independently (JN, SAF and FS), the results were compared and the coding frame clarified where necessary. The computer package NUD*IST (Non-numerical Unstructured Data Indexing, Searching and Theory building) was used to assist with data management.

Quantitative procedures (frequency analyses), with the use of SPSS, were employed to describe the characteristics of the sample, places of storage of medication or items related to the condition, parents' reports of the presence of a policy regarding medication in school and other systematically collected quantitative information.

RESULTS

Sample characteristics

Sixty three GP surgeries participated in identifying and recruiting the study sample. In total, 43 young people with asthma and their parents (response rate 11%) and 26 young people with diabetes and their parents (response rate 30%) were interviewed (138 interviews in total).

In the vast majority of instances independent interviews were carried out. In two cases in which the young person was interrupted by their parent, the parent was reminded, and accepted, that the researcher wished to focus on the young person's views at that point. The mean length of interviews in the asthma part of the study was 28.7 min for parents and 17.4 min for young people, and in the diabetes part of the study the mean length was 46 min for parents and 19 min for young people.

Schools were spread across seven local education authorities (table 1). Five of the primary schools were identified as small village schools and five young people attended independent schools.

The perspectives of young people

Access to medication whilst at school

Five of the 43 young people with asthma did not take medication or items relating to the management of their condition to school, whilst the remaining 38 took preventer or reliever medication. All young people with diabetes took items related to their condition to school, which included blood glucose monitoring equipment, insulin injections, blood testing strips, fizzy drinks, glucose tablets and food items.

Young people were asked where medication and other items relating to their condition were stored in the school (table 2).

Most young people who carried their own medication used it when they perceived the need without seeking permission.

Table 1 Sample characteristics presented by condition of young person (n = 69)

Sample characteristics	Sample with asthma (n = 43)	Sample with diabetes (n = 26)
Sex		
Male	27	12
Female	16	14
Age (years)		
Mean	10.5	11.7
Range	8–12	8–15
Mean number of years since diagnosis	6.2	4.8
Number of mothers interviewed	38	17
Young people attending primary school	32	12
Young people attending lower school*	0	1
Young people attending middle school*	1	0
Young people attending secondary school	10	13
Number of parents self-identified as from a white ethnic group	40	26
Number of parents reporting owning their homes	37	21

*Young people attended schools beyond county boundaries, lower school aged 5–8 years and middle school aged 9–13 years.

All young people whose medication was stored in a room away from the classroom or with a member of staff reported that they had to seek permission to use it; this was perceived and experienced as a problem. Two young people with asthma reported being encouraged by their parents to hide inhalers so that they would have them with them:

We are meant to put our hand up and ask Miss for our blue (inhaler) but then I'd have to walk all the way to the office to get it. So my Mum she said to me just to keep it in my pocket or my pencil case and just use it when I need it. She says if I get caught just to tell the teacher to speak to her about it, but she [teacher] doesn't really notice me when I use it.
Kelly, aged 11 with asthma

Use of medication at school

Young people with asthma did not report problems with the administration of their medication; however, one young person reported:

Table 2 Storage of medication or items related to condition in schools, as reported by young people

Place medication stored	Young people with asthma (n = 38*)	Young people with diabetes (n = 24†)
With young person	22	9
Room in school away from classroom	8	4
With teacher or welfare staff	8	0
In classroom	0	10
School office	0	1

*Five young people with asthma did not take medication to school.

†Two young people with diabetes did not take items relating to diabetes to school.

Well at home mum would help me with the puffer [use of inhaler] but at school I have to do it on my own, which I think is harder.

Hilary, aged 10 with asthma

Three respondents administered insulin when at school. They all reported problems with the lack of a private location within the school where they could administer injections. Two young people reported administering injections in the toilet which they described as cramped and unsatisfactory:

There isn't really much of a place you can do it [administer insulin injections]. There is one place, the first aid room, but there's all windows about where the playground is, so there is no place you can do it without people seeing you.

Grace, aged 13 with diabetes

Impact on regimen

Young people described how the structure of the school day or school policies led to difficulties maintaining their regimen. For young people with asthma, problems tended to occur only when they were unwell and needed additional medication, such as antibiotics which needed to be taken during the day.

For those with diabetes, however, the maintenance of their regimen presented difficulties at school. Most problems related to food, for example, being forbidden from eating snacks and the timing of school lunches, which made it difficult to control blood glucose levels.

The role of teachers and "informed friends"

Young people with both asthma and diabetes most frequently described seeking assistance from teachers when they began to feel unwell due to their condition. However, only two young people (both with asthma) who had sought help from teachers were positive about the assistance they received. More commonly, young people described staff as being unsympathetic to their condition or disbelieving of their symptoms or difficulties.

Seven young people described relying on "informed friends" when in difficult situations at school due to their condition. They each described a close friend or couple of close friends who were aware of their condition and the required treatment and who were able to get the attention of the teacher when the young person was too unwell to do so themselves:

I started to feel really weird and like I was shaking and getting sweaty and I felt a bit strange so I couldn't really tell Mr Simms and speak and he kind of just looked at me weird and asked if I was ok, but luckily Harvey (a school friend) knew what was wrong and he went to my box and got the Lucozade and gave it to me and it was ok ... my friends said Mr Simms was just sort of staring and he didn't move.
Finlay, aged 14 with diabetes

Exercise

Whilst several young people with asthma and all those with diabetes reported little difficulty in participating in sport at school, many described strategies to accommodate their needs. For example, their mother sewing a pocket into their sports kit to hold their inhaler, pacing themselves over the course of a lesson or taking positions during team games which meant moving around less. Two young people (n = 43) did report specific difficulties managing their asthma:

At school sports day I find that I can't run as fast as the other children. When we play games in the playground like It and

things like that I'm the first to get it and when we play Bulldog I'm always the first to get nominated.
Stuart, aged 10 with asthma

School trips

Participating in school trips could present additional problems and anxieties. Some schools were reported to have specific policies in relation to medication on schools trips:

Well it was frightening really to be on my own without my mum for the week, but Mum went to the school and Mrs White also came to our house and she taught her all about what I need and what to do when I go high and low and stuff. It was good in the end because I was fine, but I was scared before we went there.
Amy, aged 12 with diabetes

In another case staff had been unable to locate an inhaler when needed.

“Being different”

Three young people expressed a feeling of “being different” from their peers due to their condition; three young people with asthma and one with diabetes reporting bullying or teasing. However, in particular regarding asthma, this was not usually reported as a problem:

Question: How do you feel about using your inhaler in school?

Answer: Well lots of people do it so it doesn't bother me.
Emma, aged 10 with asthma

The perspectives of parents

Storage of medication at school

It was evident from interviews with parents that they were often unaware of practical issues regarding medication at school. Some parents were unable to answer questions relating to where the young person's medication was stored at school or what happened when they wanted to use it. Many parents were unaware of whether or not there was a medicines policy at the school (table 3).

Anxieties regarding policies were commonly expressed. In particular, parents of young people with asthma were most often worried that the storage of medication outside the classroom would cause delayed access in the event of an asthma attack.

Five parents of young people with diabetes ($n = 26$) were unhappy that school policies meant that behaviours encouraged within the home to ensure good diabetic control, such as regular snacking and monitoring blood glucose levels throughout the day, could not be continued in school:

Table 3 Policies regarding medication in school, as reported by parents

Does your son's/ daughter's school have a policy regarding medicines?	Parents of young people with asthma ($n = 43$)	Parents of young people with diabetes ($n = 26$)
Yes	19	8
No	11	5
Don't know	13	13

It's just complete madness that they (the school) don't want her to be doing her blood sugars whilst at school, it's all to do with AIDS and that, and them not wanting bodily fluids around. But for Christ's sake it's a pin prick of blood it's not vat fulls of the stuff lying around! I went up there (to the school) and I said to the Head (head teacher) what would you rather have her safely testing her blood, or her being rushed to hospital in a coma because she can't tell what her blood sugar is?

Mother of Stacey, aged 11 with diabetes>

Transfer from primary to secondary school

Parents frequently placed emphasis on the importance of the approach of the school towards the young persons' condition. For some parents, medication policy had been a factor in choosing a particular school.

Several parents expressed concern for their child when they moved to secondary school. In primary schools, particularly village schools, parents described talking to the young persons' class teacher about their condition, but at secondary schools such contact was not possible:

I do talk to them, but in secondary school she goes all over the place - you can't, it's different teachers. Whereas in primary school it's one teacher really, so there has been less involvement now she's older.

Mother of Suzi, aged 12 with asthma

Parents' views of school staff

Some parents felt individual members of staff had been instrumental in assisting their son/daughter to manage their condition at school. In such instances, staff often had personal experience of the condition, for example a head teacher who had diabetes and a teacher who had a daughter with asthma. One parent reported that as her daughter was the first child in the school to have had diabetes, she had been instrumental in designing a policy to support young people with the condition.

However, negative views of school staff were common. Parents of young people with both conditions perceived staff as unsympathetic to the needs of their sons/daughters, unaware of the serious nature of the condition and lacking in sufficient knowledge to know if the young person was having difficulties. These perceptions applied to both conditions but were particularly prevalent amongst the parents of young people with diabetes:

...oh, it is a concern you know because he gets to a certain stage when he really does not know what is going on, it's like when someone is completely drunk and they are just incapable of communicating or moving. I just sometimes think ... if he was slumped over his desk would they notice? What if they didn't see? How long could he be there?

Mother of Rupert, aged 14 with diabetes

I mean it's frustrating for us parents, when you have the medicine there and you know all she (the teacher) has to do is make sure he takes it. But then you hear stuff about teachers being sued for touching kids, and you think they have to be really careful you know, they have to cover their own backs.

Father of Nick, aged 9 with asthma

DISCUSSION

These experiences of young people with asthma or diabetes and their parents (total $n = 138$) indicate that young people

What is already known on this topic

- The need to train school staff regarding the management of chronic conditions and the use of medication has been identified by head teachers and researchers.
- Only limited guidance is available to schools regarding support for young people with chronic conditions and the safe and appropriate use of medicines.
- Most schools have some policies relating to medication needs.

What this study adds

- Young people try to find ways to accommodate their medication and condition related needs whilst at school.
- Young people and parents reported that effective management of their conditions was complex and may be further hindered by school policies.
- To ensure optimal care, protocols tailored to the needs of young people with different conditions need to be developed.

endeavour to find ways to accommodate their medication and condition related needs whilst at school, in an attempt to limit the impact of their condition upon school activities such as sport, school trips and relationships with peers.

However, difficulties could be exacerbated by school policies which were not supportive of good management, in particular in relation to ensuring timely access to medication and a suitable location for its use. As indicated in previous studies,^{7, 8} most young people had access to medication at school. However, this in-depth research shows that young people may not have speedy access. This is a concern which young people and their parents often attempt to work around, but there are potential consequences for the effective use of medication. For example, the practice of hiding an inhaler and using it discreetly, so as not to be seen, will prevent a good technique essential for effective drug delivery and therapeutic outcome. Only three of 26 young people regularly administered insulin during the school day. Moves towards more frequent monitoring of calorific intake, blood glucose levels and administration of insulin may lead to a higher proportion of young people with diabetes administering medication or monitoring their condition at school. School policies must support this more intensive management in terms of ensuring appropriate access to medication and a suitable environment for condition management.

Particular concern was expressed, and difficulties reported, around the management of deterioration in a young person's health or a potential crisis. Previous research in the USA has shown the school nurse to have an important role in such situations.¹⁰ With few schools in the UK now having support from a medical nurse, the responsibilities of school staff in relation to medication are unclear. Although the viewpoint of teachers was not an objective of this research, some parents acknowledged the difficult position of teachers in intervening in such situations. Guidance to schools on medication^{4, 5} has failed to assist teachers in clarifying their legal position should they be required to assist a young person with a medical difficulty, particularly if at a later date their actions are deemed incorrect. Young people themselves reported relying on their peers for assistance; while in some

situations this may be helpful, in the case of a serious medical emergency this resort is clearly inadequate.

CONCLUSION

Currently, arrangements to support appropriate medication and condition management in schools seem variable and often unprepared. This is clearly a concern to young people with a chronic illness, creates parental anxiety and will jeopardise good management of the condition. In order to ensure optimal care, there is a need for the development of protocols tailored to the needs of young people with different conditions. These should preferably be devised in partnership between the young person, their parents and the school to ensure that they offer the flexibility and support required for optimal management.

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Authors' affiliations

J Newbould, S-A Francis, F Smith, Department of Practice and Policy, School of Pharmacy, University of London, London, UK

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REFERENCES

- 1 Williams C. Alert assistants in managing chronic illness: the case of mothers and teenage sons. *Sociology of Health and Illness* 2000;**22**(2):254–72.
- 2 Prout A, Hayes L, Gelder L. Medicines and the management of ordinariness in the household management of childhood asthma. *Sociology of Health and Illness* 1999;**21**(2):137–62.
- 3 Gabe J, Bury M, Ramsay R. Living with asthma: the experiences of young people at home and at school. *Soc Sci Med* 2002;**55**:1619–33.
- 4 Department of Health. *National Service Framework for Children, Young People and Maternity Services: key issues for primary care*. London: Department of Health, 2004.
- 5 Department of Education and Employment. *Supporting pupils with medical needs: a good practice guide*. London: DfEE Publications, 1996.
- 6 Wong ICK, Awolowo T, Gordon K, et al. Survey of administration of medicines to pupils in primary schools within the London area. *Arch Dis Child* 2004;**89**:998–1001.
- 7 Pugh E, Mansfield K, Clague H, et al. Children with asthma in schools: an opportunity for healthy alliances between health and education authorities. *Health Trends* 1995;**27**(4):127–9.
- 8 Fillmore EJ, Jones N, Blankson JM. Achieving treatment goals for schoolchildren with asthma. *Arch Dis Child* 1997;**77**:420–2.
- 9 Lightfoot J, Wright S, Sloper P. Supporting pupils in mainstream school with an illness or disability: young people's views. *Child Care Health Dev* 1999;**25**(4):267–83.
- 10 Carroll AE, Marrero DG. The role of significant others in adolescent diabetes: a qualitative study. *Diabetes Educ* 2006;**32**(2):243–52.
- 11 Taras H, Potts-Datema W. Chronic health conditions and student performance at school. *J Sch Health* 2005;**75**(5):255–66.
- 12 Ayala GX, Miller D, Zagami E, et al. Asthma in middle schools: what students have to say about their asthma. *J Sch Health* 2006;**76**(6):208–14.
- 13 Tatman MA, Lessing DN. Can we improve diabetes care in schools? *Arch Dis Child* 1993;**69**:450–1.
- 14 Cicutto L, Murphy S, Couits D, et al. Breaking the access barrier: evaluating an asthma center's efforts to provide education to children with asthma in schools. *Chest* 2005;**128**:1928–35.
- 15 Shah S, Peat JK, Mazurski EJ, et al. Effect of peer led programme for asthma education in adolescents: cluster randomised controlled trial. *BMJ* 2001;**322**:583–6.
- 16 Faro B, Ingersoll G, Fiore H, et al. Improving students' diabetes management through school-based diabetes care. *J Pediatr Health Care* 2005;**19**(5):301–8.
- 17 American Diabetes Association. Care of children with diabetes in the school and day care setting. *Diabetes Care* 1999;**22**(1):163–6.
- 18 Reading R, Jones T, Upton C. Emergency inhalers in school. *Arch Dis Child* 2003;**88**:384–6.
- 19 Zoritch B, Eiser C, Hiller EJ, et al. Cystic fibrosis and school: the teachers' viewpoint. *Ambulatory Child Health* 1996;**1**:302–10.
- 20 Jarman B. Identification of underprivileged areas. *BMJ* 1983;**286**:1705–9.
- 21 National Digital Archive of Datasets. Data for health authorities (boundaries at April 1996) Underprivileged area scores (Jarman scores). 1996. Available from <http://ndad.ulcc.ac.uk/CRDA/24/DS/1996/4/3/display.html> (accessed 17 September 2007).